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ABSTRACT

Sex education for individuals with autism needs to be a part of planned instructional programs covering a variety of settings and foci, from health and hygiene to social skills and dating. The manner and amount of detail during the instruction will depend on the functioning level of the person being taught and what teaching strategies are most effective for that individual. The individual's behavioral repertoire must be assessed in the areas of observed sexual expression, development of modesty, interactions with others, awareness and acceptance of self, and self-care and hygiene. Concepts that could be included in social/sexual training include: growth and development; modesty; public and private; respect of privacy; differentiating among friends, family, acquaintances, and strangers; doing something about sexual feelings; and learning about "safe" sex. Techniques for teaching various social/sexual concepts and behaviors are discussed, such as establishing a menstrual routine, learning about appropriate touching, dating, and masturbation. (JDD)

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The University Affiliated Program of Indiana

FUNCTIONAL PROGRAMMING FOR PEOPLE WITH AUTISM: A Series . . .

SEX EDUCATION: ISSUES FOR THE PERSON WITH AUTISM

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By
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Institute for the Study of Developmental Disabilities

c. 1991

INTRODUCTION

We are just beginning to address some of the areas people take for granted as being part of a "normal" life or existence. One of these is the sexual needs of people with autism. Without program planning and instruction, people who are severely handicapped frequently have no opportunity for these needs to be expressed and developed, particularly in appropriate ways that would be valued by individuals who are not disabled. The types of control that are still commonly exerted over the lives of people with developmental disabilities are such that sexual expression is often accompanied by confusion, ignorance, repression, inappropriate outlets, and victimization. For example, it is not unusual for an individual who is developmentally disabled to be a victim of unwanted sexual activities or engage in inappropriate behavior in public because of a lack of sex education and counseling as well as a lack of opportunities to develop more appropriate, self-initiated sexual outlets.

Incidental learning of sex information and appropriate, socially acceptable behaviors occurs much less frequently among individuals with disabilities. This is particularly true for people with autism who may not generalize well or learn from more abstract material, and may have problems with social relationships in general. Because most people with autism do not have close friends, have difficulty understanding their own feelings and the feelings of others, and do not easily engage in reciprocal social exchanges, it is almost impossible for such individuals to know what actions and expressions of feeling are "normal" and acceptable. They have difficulty interpreting their own and others' sexual feelings or affectionate actions as well as responding appropriately to sexual needs without careful instruction. The necessity for sex education for people with developmental disabilities is critical in light of the prevention of unwanted pregnancy, sexually transmitted diseases, the risk of sexual abuse, and the enhancement of self-esteem and adaptive behaviors. A positive

sexual self-image is important to one's whole self-image and to social adjustment as well.

To be most effective sex education needs to be a part of planned instructional programs covering a variety of settings and foci; from health and hygiene to social skills and dating. The manner and amount of detail during the instruction will depend on the functioning level of the person being taught, and what teaching strategies are most effective for that individual. Obviously, small group lectures would not be appropriate for sex education instruction for the severely handicapped person, or for most people with autism. Instruction for these people may involve the use of photographs or pictures, teaching and practicing some basic rules of conduct, modeling, and scheduling private time and what private times are to be used for.

ASSESSMENT

Staff constructed behavioral checklists and interviews with caregivers can be used to assess a person's behavioral repertoire in areas of observed sexual expression, development of modesty, interactions with others, awareness and acceptance of self, and self-care and hygiene. The area of social interactions needs to include behavior with strangers and friends, as well as possible sexual partners. Further, the individual must be able to discriminate among these relationships. Also, the issues involving giving consent and avoiding unwanted sexual advances need to be assessed. Care of self should include cleanliness, undergoing doctor examinations, care of menses, use of contraceptives, and practices to avoid sexually transmitted diseases.

The Home Life Assessment Checklist, developed by staff at the Institute for the Study of Developmental Disabilities includes the following:

- Has a working definition of the meaning of private
- Displays awareness of sexual development
- Identifies private body parts
- Displays acceptance of own sexual development/sexuality
- Discriminates between private and public conversational topics and uses these topics appropriately
- Uses private objects and belongings appropriately
- Undresses only in appropriate places
- Does private touching in private
- Discriminates between appropriate and inappropriate interaction with others
- Participates in appropriate social/sexual interaction with others

Recommendations Based on a Survey of 100 Parents about Sexual Issues and Their Children with Autism

- Rules about private behaviors were more likely to be taught to and thought to benefit the individual with higher cognitive skills who was verbal. Yet individuals with autism regardless of functioning level displayed inappropriate behaviors. This suggests that probably all persons with autism need to be taught practical, applicable rules governing social/sexual behavior.
- Persons with verbal skills tend to receive more information regarding sexuality than those who are nonverbal; thus, more attention needs to be given to teaching individuals without verbal skills. Because most individuals receive this training in schools, these settings must be particularly attentive to teaching and training. The understanding of verbal individuals needs to be monitored and assessed carefully.

- Parental concerns include child's vulnerability to molestation, AIDS, venereal disease, others' misunderstanding and misinterpreting their child's behaviors, and daughter getting pregnant. Parents also reported concern of their child not having the opportunity to enjoy a sexual relationship. Parents need more information and help.

- The most frequently asked question from parents is how relevant sexual relations are for persons with autism. Other questions were: a) should birth control be practiced, b) what is the best method of birth control, and c) do persons with autism have children? Parents need to be able to discuss their concerns with knowledgeable people.

- Parental attitudes toward sexuality vary across the spectrum. Thus, their beliefs/attitudes cannot be generalized.

- A sex education package geared toward individuals who are non-verbal or minimally verbal with autism needs to be developed.

- Parents' concerns were related to the gender of their child. Parents of males were more worried about their son being taken advantage of by the same sex person, and conversely parents of females were worried about their daughter being taken advantage of by an opposite sex person. Parents' concerns need to be discussed and programming for the individual must address needs.

DEVELOPING OBJECTIVES

Knowledge of autism is necessary in planning an instructional program. Each person's skills and behavior may vary considerably so it is important that goals and objectives be "individual specific." Some objectives may be site specific as well, as in "Private touching is to occur only in one's bedroom at home," or "Sexual intercourse should occur in private, after contraceptive is in place." When teaching people with autism it is important that instructions be clear, specific, and concrete. Because of the long-standing nature of learned behviors, some of which may be inappropriate, teaching a new behavior may take more time than expected with many repetitions. Because of difficulties understandng the concept of choice, and confusion interpreting sexual feelings, a scheduled private time to masturbate may have to be arranged by staff/parents. Laster, the person may learn to request private time or to choose that over another free time activity.

Objectives are planned based on specific assessment needs, as well as taking into account residential and community parameters. A person with a high sexual drive, for example, may need to learn that it is acceptable to masturbate in a public restroom, if there are private stalls. Another individual may need to be taught not to masturbate in the restroom at the workplace because of lack of privacy or because of time considerations, and that s/he needs time for this before going to work.

The following are examples of concepts which could be included in social-sexual training:

1. Learning About Growth and Development

    a. Changes in body

    b. Menstruation

    c. Ejaculation

    d. Breast development

    e. Hair growth

2. Modesty

    a. Where to undress?

    b. Where to be nude?

    c. Who sees you nude?

3. Public and private

    a. What places are private?

    b. What behaviors are private?

    c. Private behaviors are done in private places.

Practice identifying these in pictures or photographs and in real situations.

4. Respect of privacy.

5. Differentiating between friends, family, acquaintances and strangers.

   a. What to do when meeting a stranger.

   b. Demonstrate appropriate greetings and responses. These should be role-played, reinforced in real situations, or possibly videotaped so the individual can identify the correct behavior.

   c. Adolescents and adults with disabilities often need to be taught specifically how to show affection in appropriate ways. For reasons of safety, they need to be taught when touching (from others) is not appropriate and who to tell if they are approached. For each way of appropriate touching (hugging, shaking hands, patting an arm or back) times and places for such contact and who can touch need to be specified. A set of instructional cards could be made which set the guidelines.

   d. Dating skills can be defined and systematically taught if the individual wishes to initiate a romantic relationship.

6. How to do something about sexual feelings.

   a. Learn to masturbate.

   b. Keep active.

   c. Learn to seek appropriate partners.

7. Learn about "safe" sex.

Objectives for social/sexual instruction may vary considerably based on the individual involved. Here are two examples of instructional objectives:

SUE

1. Sue will identify 10 body parts on herself and others.
2. Sue will identify places and activities as private.
3. Sue will masturbate in private.
4. Sue will masturbate with safe objects or her hand when on her bed with her vibrating pillow.
5. Sue will only initiate a conversation with persons whom she has met previously.

JOHN

1. John will appropriately reject stroking and rubbing from others except from those on his list.
2. John will discuss private topics only with individuals he knows well, in private places.
3. John will use a condom during sexual intercourse.
4. Sexual intercourse will take place in private, with a consenting adult.

TEACHING SOCIAL/SEXUAL CONCEPTS AND BEHAVIORS

Adolescence is defined as the period from the beginning of puberty until maturity. This is a gradual process and the physical changes which accompany puberty vary from individual to individual. Puberty is that period in life when boys and girls experience physiological changes making them functionally capable of reproduction. Along with the physiological changes, the

intensity of the sex drive is increased. The individual with autism experiences this innate sex drive but is often confused by it.

Sex education must be a part of the curriculum for adolescents with autism for several important reasons. The individual may engage in behaviors of masturbation and/or genital touching. The young woman experiences the onset of menses. The individual may be vulnerable to sexual abuse, particularly due to the lack of knowledge of growth and development. Additionally, the adolescent with autism may exhibit a general excitement and high activity level that might be associated with sexual arousal, making it mandatory that sexual issues be directly addressed.

Learning about Growth and Development

Another part of sex education is learning about growth and development. For some individuals this may include distinguishing children from animals or adults. For others this may be distinguishing men from women, boys from girls. The individuals might not understand the continuum of development and through the use of pictures of self and others see growth from infancy to adult. This is usually learned early in childhood, but with adolescents with autism who often are not able to interact effectively, these concepts must be taught.

Learning the names of the body parts is important so the adolescent can use these words when communicating. It is especially important when a person develops pain in the genital area that he/she communicate that to others. Body labels include penis for the males, and breasts and genitals for the females. Genitals rather than clitoris, urethra, vagina can be used for simplicity.

Real pictures, films and videos, mannequins and models of body parts are available to provide more concrete training. Association with the student's own body must be made clear.

Establishing a Menstrual Routine

Depending upon the individual's functioning level, she may learn by imitation, or a visual checklist, or may need more intensive training with a reward system built in. Teaching menstrual hygiene independence to a lower functioning woman with autism may be an arduous task, but it is important if she is to function with a degree of independence.

Procedure:

When Mary begins her period she will wear long pants each day until the end of her period. Every two hours Mary will change her pad when she's on her period. She may have to be cued. She will carry a card each day and cross out the hours; 8:00, 10:00, 12:00, 2:00, 4:00, 6:00, 8:00. She will put the used pad in a paper sack, and throw it away. (She needs to carry the sacks with her pads in her purse). Sacks should be available in her room. The paper strap from the pad backing goes into the waste paper basket. Mary needs to wash her hands after bathrooming and after changing her pad (whether she toilets or not).

Learning About Appropriate Touching

Teaching the autistic adolescent self protection is a difficult task. Begin by teaching the person to touch himself/herself only in one or two private places, like the bathroom or bedroom. He/she will have to be taught that there are places like the doctor's office where someone else might touch and that this is okay. The list of the people allowed to touch his/her "private areas" needs careful instruction. We currently know little about teaching this abstract concept. However, as people with autism gain more freedom and independence in communities and as they learn to interact and trust more people, it is an area that needs further investigation.

Overprotection and a lack of instruction can promote the sexual victimization of people with developmental disabilities. It is critical to include instruction regarding the prevention of sexual abuse in every person's habilitation plan. This instruction should be individualized to meet the needs of each individual depending on cognitive skills, life style, communication skills, and best learning mode. This type of instruction can begin in childhood and should be carried through with adults. Role modeling and films can be used with individuals who can learn from this type of presentation. In a teaching resource called Circles (James Hanfield and Company, STA P.O. Box 1983A, Santa Monica, CA 90406) students are taught to respond to people based on their relationships to others. The basic guidelines are:

1. You are the most special person in the world.
2. No one touches you unless you want to be touched.
3. You do not touch anyone unless they want to be touched.
4. There are very few people who hug you-mother, father, boy/girlfriend, sister/brother, grandparents.
5. There are a few more people to give big hugs to, such as your best friends on their birthdays.
6. You shake hands with acquaintances.
7. You wave to children.
8. You do not touch strangers.
9. Strangers do not touch you.

(Remember that negation is often not processed by people with a communication handicap. Explain by specifying or teaching what to do).

Even more specifically, this training could include modeling of who is a stranger, and ways to react if inappropriately approached or touched by a stranger, or touched by someone in a way that makes one uncomfortable. Cards can be used to rehearse the "rules" then as cue cards when an inappropriate behavior occurs.

Example: Hugging

Who: Family members (list) Friends (list)

When: Saying hello or goodbye, or at bedtime

Where: At home, in private, on the couch, etc.

Dating

Some individuals with autism may wish to form closer friendships or become romantically involved with another person. Social interaction skills need to be taught for this to happen successfully. Introducing oneself, letting the other person know of one's interest in him or her, and being able to tell whether the interest is reciprocated are important beginning skills. Other skills to be taught include asking the person for a date, how to handle a rejection, and how to negotiate or compromise on where to go and what to do on the date. How to touch and what rules govern touching in varied places will need attention.

Teaching these social skills will be a challenge because subtle social cues are difficult for a person with autism to pick up and interpret correctly. Role playing situations in a small group of peers with a facilitator may help. Rules may need to be formulated and written out on how to negotiate: the first date Joe chooses the activity, the second date Susan does. Generally a person with autism does not learn well in a discussion group format. Using written situations and choices may help comprehension. Simplifying the give and take of social relationships into rules to be memorized and followed may be necessary.

A mentor may need to be identified; a person who is always available to the individual with autism to help problem solve and explain the social intricacies of forming and expanding interpersonal relationships. This person might be a teacher, school counselor, parent, therapist, or peer.

Masturbation

Masturbation or touching of the genitals occurs frequently in some adolescents with autism. This can be a way to relieve sexual pressure and tension. It may also show that the student is more aware of the genital area. The adolescent with autism may masturbate in an unusual position or with an unusual object. This might be how he first became aware of sexual stimulation or he might have been repeatedly told "no" when he has touched his genitals so he has learned to touch indirectly. Masturbating on table legs; with one foot; or with an object, such as a blanket may become part of the masturbation routine. These methods may be inefficient and may increase sexual frustration in some people. Males may also have erections when in contact with external stimuli such as special objects or body parts associated with their masturbation routine.

Since masturbating is a way to relieve the sex drive and possibly produce a relaxation response, the individuals with autism should be allowed to masturbate or touch his/her genitals. However, since this is "private" behavior, the individual should be taught the concept of "private" when he/she begins to masturbate or touch genitals. "Private" may come to mean, to do all by oneself with door closed. Places where private behaviors can occur should be designated, then defined through practice. Statements such as "That's private, do it in your bedroom", then taking the student to that place will teach this concept over a period of time. Use a consistent approach.

Sometimes, the individual with autism has been punished or told "no" when he/she touched his/her genitals. He/she needs to learn that it is okay to touch, but only in private. Therefore, bedrooms are only used as private places, not for sit out or time out areas. Bedrooms are places where the individual can do what he likes to do such as play records, rock, or listen to the radio. A bathroom may be designated as the private place, particularly if the person is upset by the bed or clothing getting wet when ejaculation takes place. However, for others the bathroom may be negative due to toilet training problems. Also, a male may need to be taught that while urinating he needs to touch his penis to direct the flow. Sometimes the lesson of "Don't touch" is taken to mean never, anywhere.

The person with autism may seem unaware of the meaning of sexual urges. The individual with autism may need careful training and patient education as he matures. Specific objectives and plans for implementation should be developed. Examples follow:

Objective: Private behaviors are done in private places

Teach the individual to distinguish between private and non-private places, using pictures of familiar places, i.e., toilet at home, the individual's bedroom, the living room, the classroom or workplace. Most of the teaching can occur in the classroom and home environment where individuals can be told when they begin touching their genitals- "That's private touching, do it in the bathroom at home." For many individuals learning that private behaviors are done in a private place through practice is the most concrete way to teach this concept.

Objective: Follow a masturbation routine in private

Masturbation or genital touching that is inefficient is a dilemma. The individual must be given ample time for stimulation, but it should not be allowed to interfere with planned activities. More efficient ways to masturbate may be taught through the person's

best mode of learning. Also, time for masturbation can be built into the schedule. The individual may need to be awakened earlier than usual or allowed to go to bed earlier than the usual bedtime or given "private time" before supper. Plans for privacy will have to be arranged for individuals sharing bedrooms or bathrooms.

Masturbating to climax may be upsetting to some male clients. Many of them received arduous training to learn to urinate in the toilet. Masturbating in bed, once ejaculation has occurred, gets the bed wet. This is confusing to the person. The distinction between urinating and ejaculation is not clear, and it is difficult to explain. Reassurance may be needed.

A Procedure for Establishing a Masturbation Routine

Rationale:

1. To teach client how to physically/sexually satisfy himself/herself or reduce sexual frustration by self-manipulation.

2. To reduce number of aggressive behaviors by reducing frustration.

3. To help spend his/her time more productively; go to private time less during the day.

4. To let client know that this behavior is acceptable if done in private. Have a therapist who does not work with the client do the training, then transfer to an initial cue only.

Environment: In bedroom, on bed-private time.

Cue: Green light on.

I. Verbal Cues (or use visual cue cards or sequence)

1. "Time to masturbate."
2. "Pants off"
3. "On stomach"
4. "Rock"
5. "On back"
6. "Fingers"

II. Repeat cues one at a time. These cues mean:

1. "Take pants off"
2. "Lie on stomach and rock from side to side"
3. "On back and rub his penis with his fingers"
   Reduce cues as he can proceed by himself. Reward 10 pennies at end of allowed time. (Pennies are his familiar token reinforcement system).

Allow 20-30 minutes each time when possible. Training time may be longer.

Long Term Plan:

Reduce cues.

Use green light as cue to start.

Self-initiates by asking for private time.

Masturbation Using A Condom

Teaching a masturbation routine which includes use of a condom is another option. A condom will prevent the bed clothes from getting wet during ejaculation and fears about wetting the

bed. The individual may be able to clean himself and the environment more easily if he has used a condom. Also a condom will decrease the chances of infection caused by dirty hands or objects.

The condom can become a stimulus cue for the masturbation routine. The individual will only masturbate when a condom is available. This allows the behavior to be restricted to appropriate times and places.

If the person does eventually make the decision to become sexually involved with another person, the routine use of a condom and safe sex will already be part of his behavioral repertoire.

Masturbation Using a Vibrator

Hand held vibrators or vibrating pillows can also be used in a masturbation routine for a person with autism. The routine might start with the individual massaging herself with the virbrator on her arms, legs, chest and stomach. Written, pictured, or verbal sequences can cue the routine. A timer can be used to cue the duration of the routine. Staff could teach the routine by massaging the individual's arm and legs with the virbrator and then start the timer and exit the room.

The vibrator probably will become a stimulus cue and will help the individual distinguish where and when private behavior can take place.

CONCLUSION

Sex education is a vital part of the program for the adolescent and adult with autism. The education is best carried out in a consistent way throughout the person's life. The teaching must be geared to the functioning level and basic sexual drives of the individual.

Our involvement in planning programs for people with developmental disabilities gives us a position of power and control over the lives and behaviors of others. It behooves us then, to be thoughtful and nonjudgemental in regard to this process and its results. Although it may be difficult for us to admit, all people are sexual beings and have certain rights. No one has the right to limit or control the sexual expression of others provided that other peoples' rights are not being infringed upon, and the individual knows how to prevent pregnancy. All people have the right to privacy, the right to be informed, the right to make choices, and the right to develop to one's fullest potential.

As community integration becomes a reality for people with disabilities, program planners and parents need to become more sensitive to and astute in addressing the social and sexual needs of individuals. There are many more opportunities and choices for people when they are living and working in the community. Social and communication skills become much more essential and enhance the experience of participating in the community with people. To succeed in the community means to behave in socially acceptable ways, as well as to be able to take advantage of the options available, and to interact successfully with other people. In a segregated environment it is easy to overlook certain inappropriate behaviors, which may further separate and handicap a person who is interacting in the community. Social/sexual instruction thus becomes vital to successful integration and growing independence and must address the risks as well as the rights of each individual.

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